

# **I. Summary**

## **A. Background**

From March through December of 2005, the HIV/AIDS Planning Council for the Seattle Eligible Metropolitan Area (EMA) conducted a comprehensive needs assessment of Ryan White Care Act (RWCA) funded HIV/AIDS care services in King County.

The 2005 Needs Assessment was a research and planning activity that sought to:

- identify the extent and types of existing and potential care service needs among low-income persons living with HIV/AIDS (PLWH) in King County;
- examine the current service delivery system in the County, particularly the system's ability to ensure that PLWH can effectively obtain and maintain access to primary medical care and treatment as well as other vital HIV-related support services;
- determine the extent of unmet needs and related barriers in order to plan appropriate care services;
- analyze and compare two-year trends in service utilization, priorities and gaps, and
- determine and describe barriers to services for traditionally underserved and severe needs sub-populations.

The main objective of the 2005 Needs Assessment process was to provide data to inform decisions related to the Planning Council's prioritization of care services for the Ryan White Care Act's Title I funding allocation process. Additional goals of the project were to:

- assess the current Continuum of Care in Seattle-King County, with the goal of strengthening the system and working towards greater collaboration among diverse communities and service systems;
- provide legislatively mandated information to the federal Health Resources Services Administration (HRSA) on service needs and system response;
- provide planning information for agencies, organizations, and health care providers;
- collect information from as wide a spectrum of PLWH in King County as possible who were consumers of RWCA services, ranging from individuals who are HIV positive but not yet symptomatic to persons with end-state illness, and
- give particular focus to traditionally underserved populations of PLWH, including women, persons of color, persons with histories of homelessness, mental illness, chemical dependency and/or incarceration, and youth/young adults.

The comprehensive needs assessment provides a "snapshot" of community services, priorities, and gaps as identified by consumers and providers in 2005. By nature, needs assessment processes must be ongoing to reflect the changing nature of the service delivery system, treatment advances, funding availability, and epidemic trends. A similar assessment has been conducted in King County every two years since 1995, allowing for trend analysis of comparable data within this report.

## **B. Methods**

Several strategies were employed to solicit input in the needs assessment process:

- creation of a Needs Assessment Workgroup to provide guidance for the needs assessment process. This Workgroup consisted of Planning Council members, both providers and consumers, other service providers, as well as Planning Council and Public Health staff;
- creation and distribution of written surveys to PLWH throughout King County (456 surveys returned, 436 valid surveys);
- creation and distribution of written surveys to service providers throughout King County, including questions about medical care, dental care, mental health therapy, substance use treatment, and a wide range of support services (188 surveys returned);
- key informant interviews with 23 service providers, and
- focus groups conducted with 8 sub-populations of PLWH (69 PLWH participating).

Statistically significant differences were based on  $p < 0.05$ .

## **C. General Findings from the 2005 Needs Assessment**

For the consumer survey respondents, most demographic indicators were fairly representative of PLWH estimates in King County, and there were higher percentages of our respondents that were persons of color. This is aligned with the project's goal to over-sample traditionally underserved populations. The largest single response group was white MSM (53% of total). Over the last four years of the assessment process there has also been a steady increase in age of respondents, reflecting the gradual increase of the mean age of PLWH locally.

Reflective of the epidemic pattern in King County, survey respondents were most likely to report HIV transmission due to male/male (MSM) sexual activity. While this was less than the estimate for King County, we over-sampled MSM/IDU respondents compared to county estimates and non-MSM Injection Drug Users.

The consumer survey asked respondents to indicate their income level based on the most recent federal poverty level (FPL) income categories. Based on income levels and the number of dependents that lived with the respondent, 95% of the respondents met the eligibility criteria for RWCA services. Of the 74 consumer respondents who had dependents living with them, 74% had an income less than \$19,140/year (100% of the FPL).

Similar to consumer responses in 2003, 48% of the respondents reported having ever been diagnosed with a mental illness, 17% reported being homeless with no permanent place of residence within the past year, and 10% reported being in jail or prison in the past year.

In terms of AIDS disability, over half of the respondents reported being certified as AIDS disabled. From 2003, there was an increase in the number of respondents that were not certified as AIDS disabled or did not know if they had been certified as AIDS disabled. AIDS disability certification is required for some types of housing. There was also a significant increase from 2003 in the number of respondents who did not know their T-cell counts or viral loads. Three

out of four respondents indicated taking some form of antirviral medication, similar to 2003. However, consumer use of other types of HIV-related medications has steadily decreased over time (including for opportunistic infections, and side-effects).

Based on responses to demographic questions, the client population served by provider survey respondents is fairly representative of PLWH in King County. Efforts to over-sample among providers who serve women, persons of color, MSM/IDU, and non-MSM were successful based on demographic frequencies. While the average caseloads for medical providers and mental health providers decreased from 2003, there was a dramatic increase in the average caseloads reported by case managers, from 78 in 2003 to 137 in 2005. There has been an increasing trend in the average caseloads of MSM/IDU: 2001 (9%); 2003 (13%); 2005 (18%).

Providers reported seeing a higher percentage of clients from the areas of King County which are outside of Seattle than appear in King County PLWH estimates of residence at diagnosis of HIV. This trend has been apparent over the last four years from provider surveys. The most significant difference in residence over the past two years is King County providers reporting that 15% of their caseloads are consumers who live outside of King County (an increase from 6% in 2003). Based on consumer surveys, Black/African American and female respondents were significantly more likely to reside in South Seattle. There is also an increasing trend over the past four years of the number of providers who report seeing one or more clients who were primary speakers of languages other than English or Spanish.

On average, providers reported increases in the percentages of their clients who were homeless, diagnosed with mental illness, and/or had a history of chemical dependency. The provider interviews and consumer focus groups emphasized the severity of these co-morbidities.

## **D. Service Priorities**

Consumers ranked case management as the highest service priority, with 69% of respondents indicating that it was a priority for them. Case management was followed by ambulatory outpatient medical care, AIDS Drug Assistance Program (ADAP), oral health care and food bank/home delivered meals. Case management had the most significant increase in priority and has increased in consumer priority over the past four years. Treatment adherence support and Alternative non-Western therapies also increased significantly in the percentage of consumer priority. Emergency financial assistance was the only service category with a significant decrease in consumer priority.

Several differences emerged in the ways in which consumer sub-populations prioritized services based on race, exposure category, foreign-born status, and gender:

- White MSM were significantly more likely to prioritize ambulatory/outpatient medical care, and mental health services.
- MSM/IDU were significantly more likely to prioritize food bank/home-delivered meals, housing assistance/related services, day/respite care for adults, and client advocacy.
- MSM of Color were significantly more likely to prioritize housing assistance/related services, and substance abuse services.

- Black/African American respondents were significantly more likely to prioritize food bank/home-delivered meals, housing assistance/related services, treatment adherence support, emergency financial assistance, legal services, and child care.
- Latino/Latina respondents were significantly more likely to prioritize client advocacy, and emergency financial assistance.
- Respondents who were not born in the US were significantly more likely to prioritize legal services and substance abuse services.
- Women were significantly more likely than men to prioritize psychosocial support, emergency financial assistance, home health care, and child care.

Like consumer respondents, providers ranked case management as the highest service priority for their clients, followed by ambulatory/outpatient medical care, mental health services, AIDS Drug Assistance Program (ADAP), and substance abuse services. Substance abuse services had the most significant increase in percentage of providers prioritizing this service over the 2003 survey. Treatment adherence support, health education/risk reduction, transportation, and oral healthcare also reflected a significant increase in priority for providers. ADAP was the only service category with a significant decrease in priority for providers. However, ADAP was still ranked as a top five service priority.

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance use services and mental health counseling as service priorities. This trend continues over the past two years. Consumers were significantly more likely than providers to prioritize emergency financial assistance, oral health care, and food bank/home delivered meals

## **E. Service Gaps**

Housing assistance/related services have been a top six service gap of RWCA services in Seattle/King County for consumers since 1999. In 2005, housing services emerged as the number one service gap for consumers. Almost two-fifths of consumer respondents noted this gap. Other top ranked service gaps that followed housing services include food bank/home-delivered meals, alternative non-Western therapies, oral health care, emergency financial assistance, and psychosocial support. Twelve service categories reflected a significant increase in consumer gaps from 2003 to 2005. The housing assistance/related services category showed the largest percentage increase in consumer identified gaps to services, followed by alternative non-western therapy, ADAP, oral health care, treatment adherence support, referral for health care services, transportation, client advocacy, emergency financial assistance, home health care, substance abuse services, and day/respice care for adults.

Several differences emerged in service gaps identified by consumer sub-populations in terms of exposure category, race, gender, and foreign-born status:

- MSM of Color were significantly more likely to have gaps to housing services, alternative non-Western therapies, food bank/home-delivered meals, emergency financial assistance, legal services, transportation, substance abuse services, and day/respice care for adults. In the continuum of care, MSM of Color had more significantly higher gaps in services than any other subpopulation (8 of 20 service categories).

- MSM/IDU were significantly more likely to have gaps in housing assistance/related services, alternative non-Western therapies, food bank/home-delivered meals, client advocacy, referral for health care services, mental health services, transportation, and substance abuse services.
- Black/African American respondents were significantly more likely to prioritize transportation and child care.
- Latino/Latina respondents were significantly more likely to prioritize emergency financial assistance, legal services, transportation, and day/respite care for adults.
- Foreign-born respondents were significantly more likely to have gaps to housing services, food bank/home-delivered meals, emergency financial assistance, legal services, transportation, home health care, day/respite care for adults, and child care.
- Women were significantly more likely to have gaps in home health care and child care.

Other complicating factors including homelessness and incarceration were significant indicators of having higher service gaps.

- Respondents who are currently or have been homeless within the past year were significantly more likely to have gaps to housing services (as one might expect), and oral health care.
- Respondents who had been incarcerated in the past year were significantly more likely to have gaps to alternative, non-Western therapies, and mental health services.

Almost half of HIV-related care providers indicated mental health services, oral health care, and substance abuse services as the top three service gaps in 2005. Providers did not rank housing/services as high as consumers did and also significantly fewer providers ranked this as a service gap than in the past. However, housing services were still ranked as a top five service gap by providers. Supporting providers reported seeing more and more clients who are residing outside of Seattle in King County and for the first time in six years transportation rose to the top five service gaps for providers in 2005. Two service categories had increased significantly as gaps while three service categories significantly decreased. Transportation had the largest increase in gap by percentage. Just as for consumers, the ADAP service category which includes assistance paying for medical insurance premiums, also showed a significant increase in the percentage of providers who identified that their clients needed, but could not get, the service.

Consumers identified significant increases in service gaps for twelve service categories compared to only two significant service gap increases by providers. Providers were more likely than consumers to identify gaps with all of the core medical services (medical care, oral health care, case management, ADAP, substance abuse services, and mental health services).

The largest disparities in percentages of consumer and provider-identified service gaps emerged in the service categories of substance abuse services, mental health services, and food bank/home-delivered meals. Providers were significantly more likely to prioritize substance abuse and mental health services, while consumers were significantly more likely to prioritize food bank/home-delivered meals. Although housing assistance/related services was a higher ranking gap for consumers, by percentage, more providers indicated this category to be a service gap. Although similar in rank, 20% more providers than consumers identified oral health care as

a service gap. Three times the percentage of consumers than providers indicated a service gap to referral for health care services.

From 2003 to 2005, the disparity between provider and consumer-identified gaps diminished most dramatically for housing assistance/related services, treatment adherence support, and substance abuse services. The disparity between provider and consumer-identified gaps increased most for food bank/home-delivered meals, emergency financial assistance, and alternative/non-Western therapies.

## **F. Qualitative findings related to unmet need for RWCA services**

Survey comments, consumer focus groups, and provider interviews offered insight into unmet need for HIV/AIDS care services. In addition to looking at variations in service components within RWCA service categories, this section of the report in more detail highlights themes of information gathered through these qualitative methods (reported by consumers and providers). The following were themes of topics discussed by service category (note: emphasis on core services and other most emphasized support services by focus group participants and provider interviews):

### **AIDS Drug Assistance Program (ADAP and Health insurance)**

- *Qualification requirements are too restrictive*
- *Confusion about availability and changes to services*

### **Ambulatory/outpatient medical care**

- *Stigma about HIV exists among providers not familiar with the disease*
- *Barriers to medical care for racial/ethnic minorities (African American, LatinoMSM, and Native Americans)*
- *Barriers to care for recently incarcerated PLWH*
- *Co-morbidities: barriers to medical care for recently incarcerated, homeless, and substance abusing PLWH*
- *Barriers to medical care for women*
- *Cultural barriers for women of color*

### **Case Management**

- *Providers report that higher case management caseloads lead to inadequate service provision*
- *Disengagement reported between case managers and clients*
- *Barriers for African American PLWH*
- *Barriers for foreign-born Black PLWH*
- *Barriers for Latino PLWH*

**Housing assistance/related services**

(assistance finding housing, emergency hotel vouchers, emergency assistance paying rent)

- *Lack of affordable housing stock*
- *Lack of appropriate housing*
- *Housing eligibility requirements are too restrictive*
- *Need for collaboration between systems*
- *Issues with case management*
- *Discrimination in non-HIV specific housing*

**Mental health services**

- *Interplay of substance abuse and mental health*
- *Mental health barriers for people of color*

**Oral healthcare**

- *Limited knowledge of available resources*
- *Barriers for homeless and recently incarcerated PLWH*
- *Poor treatment, need for a greater selection among dental providers*

**Substance abuse services**

- *Need more education, outreach, and availability of treatment options*
- *Co-morbidities: need for more integration of systems*
- *Cultural competency: MSM and LGBT-friendly treatment, and need for harm-reduction integrated with traditional recovery by providers.*